

MENTAL RETARDATION SERVICES IN MANITOBA

"We Have Promises To Keep"



Martha Perske

My fears are your fears, old fears . . . of want and loneliness,
Of unknown tomorrow
Of hate often taught and intolerance bequeathed and legislated —

My needs are your needs, old needs . . . of bread and love,
Of work and peace,
Of room to grow, and time to think, and long years to live —

I fail where you fail, seek what you would find . . . question
what you would have answered —

— Walter Benton

Dear Recipient:

SUBJECT: A Report on Mental Retardation in Manitoba
"We Have Promises to Keep"

Your complimentary copy of the above-named Report is attached. The Report was submitted by Helen Steinkopf, Nicola Schaefer and Nerina Robson who did not endorse the previously released report "Challenges for Today, Opportunities for Tomorrow". This Report was prepared subsequent to our resignation to the Task Force following a meeting with Premier Pawley and the Honorable Len Evans in September, 1982; and it formulates a new direction for mental retardation services over the next decades.

You are invited to consider carefully the Report's content and recommendations for future directions.

Comments should be forwarded to:

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We look forward to your comments.

Yours very truly,

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FOREWARD

Many statements have been made by various governments about their intent and direction in providing appropriate, humane and just services to people who happen to be labelled "mentally retarded". Attempts to implement the policy were flawed by problems in design, withholding of resources, and a centralized institution-based bureaucracy. As a result, services to people with mental retardation and their families remain in drastic need of reform. The current system exercises excessive control over the lives of people, it fails to meet their basic needs, and denies them citizenship. Only with a major restructuring of the respective roles of government, the private and voluntary sectors, and consumers and the public, can we begin to deal with this critical social service problem. If direct positive action is not taken, things will get worse. Many components of the system are on the verge of collapse, and many people are in great jeopardy.

There are positive elements in the current environment: service design has advanced strikingly in the past few years; there are several excellent examples of adaptive services in Manitoba; there are many skilled and knowledgeable people in Manitoba who are prepared to work for a different future. We believe that the recommendations contained in this report provide a basis for appropriate action.

This report does not constitute a plan for the next twenty years. It does indicate a direction. It provides a basis for initiating the reorganization of mental retardation services in Manitoba, and may serve as a basis for establishing a very different working relationship between the Government and the voluntary sector. We wish to thank the Premier for the opportunity to present our views in this form.

The community is ready to enter into a partnership for change.

Nicola Schaefer
Nerina Robson
Helen Steinkopf

INTRODUCTION

The design of a human service system has a profound impact on the lives of the people who depend on its service. The more powerful the system and the more vulnerable and powerless the people, the greater the impact and the greater the tendency for the system to attempt to preserve its own power, thereby compromising the needs of the people whom it was designed to serve. People who have mental and physical handicaps are particularly vulnerable since they have traditionally been denied control over their own lives.

The way we design services for people is shaped by our basic values as a society, by our beliefs about the people served and our assumptions about their needs. These beliefs are often unconscious and not explicitly stated. Our society is set on a course of materialism, individualism and scientific self-improvement. We therefore place great value on people who are productive, physically and intellectually capable and self reliant, and devalue persons who lack these attributes.

They find themselves:

- . excluded from regular community settings and activities and from non-handicapped persons, and thus from many of the experiences and opportunities which are necessary for optimum development and inclusion in a social network;
- . disconnected from their families and their communities - from relationships which normally provide a sense of belonging, a sense that someone cares and a measure of protection and advocacy;
- . congregated with others who have been labelled and stigmatized in atypical living or learning situations;
- . seen and treated as "other" and denied the assistance necessary to meet their needs;
- . deprived of the rights and privileges accorded by the culture to all people or to people at specific chronological ages;
- . experiencing low expectations on the part of parents, teachers and other members of the community and consequently receiving reduced levels of challenge, education and personal autonomy, and reduced learning opportunities;
- . blamed and punished for their rate of development, feeling that they are a source of worry, resentment and anguish to other people;

- . growing up in an environment which lacks the information, support and confidence it requires to meet their needs and enhance their learning;
- . often incarcerated in regimented, impoverished environments without the day-to-day experiences of being loved, cared about and engaged in relationships;

The dynamics of societal devaluation and rejection, though subtle and unconscious, have a powerful and pervasive impact on the lives of people who have mental handicaps. Services to people who have mental and physical handicaps are traditionally shaped by distorted perceptions about the people and their needs. We fail to identify with people with mental handicaps and recognize that their needs are like ours, and we become preoccupied with the "differentness". Because of this focus, basic human needs are often overlooked, displaced or addressed in highly atypical and sometime bizarre ways. As a result, human services fail to meet basic needs, deprive persons of their legal and human rights, stigmatize the recipients of service, physically and socially disconnect people from natural environments such as the family and the community and at times extensively disable and demoralize natural sources of assistance. Service providers (and even parents) often create, arrange or accept living circumstances (e.g. institutions) where they would not live and in which they would not consider placing their non-handicapped children. The person who has a handicap is seen as not having the sensibility to appreciate and as not deserving of the rights and the courtesy we extend to ourselves and "our own".

The institutional response - segregate, congregate and control - whether this occurs in groups of eight hundred persons or eight, in living, learning or working situations, remains the dominant established service response to Manitoba citizens who have mental and/or physical handicaps. Vision, effort and funds are not systematically directed towards the creation of viable, individualized community alternatives.

AT THE POLICY LEVEL:

- Lack of an appropriate ideological/value base for services.
- Lack of a coherent, adaptive vision of what should be.
- Lack of unified planning and organization of service delivery.
- Lack of consumer/public participation in planning, organization, and service delivery. Persons who have handicaps, their advocates and their families do not have an effective means of participating in the planning and implementation of services to meet their needs.

AT THE RESOURCE ALLOCATION LEVEL:

- Vast majority of resources tied up in institutional services, with no way to move people and money to the community.
- Over-reliance on institutional and segregated programs.
- Over-reliance on mental retardation (disability-specific) programs and funding mechanisms.
- Lack of flexibility and responsiveness in service arrangements for individuals and families.
- A system that forces individuals and groups to compete against each other for inadequate resources.
- A pattern of under-funding which forces service providers either to deliver services of low quality, or to scratch and beg for funds, effectively crippling service development.

CONCERNING EXPECTATIONS:

- Low expectations, low levels of programming.
- "Least-cost" mentality, "it's good enough for the retarded".
- Negative image and representation of people with mental retardation and their families.
- Families made to feel inadequate, demanding, and guilty. An attitude of "be glad you have anything". Subtle and overt intimidation of unsatisfied consumers.

AT THE SERVICE LEVEL:

- Massive underdevelopment in housing, employment, personal support and family support services.
- Large numbers of people who are homeless, or in poor homes, or locked up in institutions, jobless, or in meaningless, under-challenging or exploitive jobs, poorly educated, friendless, isolated, rejected, materially/financially poor.
- Vulnerable groups inadequately served:
 - children reaching age 18 (pushed out of child welfare)
 - children reaching age 21 (pushed out of school)
 - people at home with aging parents
 - people in substandard guest homes
 - people on institutional waiting lists

- people in institutions who could be in community
- people in conflict with the law
- people who live with severe/multiple handicaps
- A system which is largely crisis-oriented.

CONCERNING ADVOCACY:

- Families without guardianship/trusteeship options ("Who can I count on - lifelong?").
- Lack of appropriate protection and advocacy services. Major violations of civil rights. Wholesale delegation of Orders of Supervision to service providers. Orders stripping away all personal and financial autonomy.
- Hostility and violent rejection towards advocacy and advocates.

AT THE ADMINISTRATIVE LEVEL:

- Community Mental Retardation Services is staffed and controlled almost exclusively by persons who were trained in and are allied with institutions.
- Lack of public accountability for program quality and outcomes.
- Minimal commitment to staff development, organizational and system renewal, and quality-based evaluation.

WHAT IS NEEDED:

...is an administration with a clear, positive vision of what can be accomplished with existing resources.

...is a commitment to a partnership with the voluntary sector - a commitment to use the talent and planning capacity of Manitoba citizens, and a willingness to utilize the experience and talents of people inside and outside of Manitoba who have made major advances.

...is a more appropriate relationship between the government, the private sector, the voluntary sector, individuals with mental retardation and their families, and generic service providers so that the talents, energies and specific role capacity of each sector can be used to the fullest.

...is a commitment to a clear, positive, articulated value base for the provision of services to people with mental retardation and their families, and a commitment to public accountability for the performance of the system.

PRINCIPLES OF SERVICE DELIVERY

Many of the problems noted above can be resolved through adoption and application of seven principles of service delivery which we believe to be essential:

Principle 1

Growth, Development, and Independence: If individuals with mental handicaps are to participate to their full potential as members of their communities, it is essential that supports they receive are focused on continued growth, development and independence. The individual service planning process -- developing and continually reviewing supports based on the individual's strengths and needs in the context of the community in which he or she lives -- is one mechanism for ensuring that this happens. Regional Boards and Corporations can be points of accountability in the Region to ensure that appropriate plans are developed and implemented for individuals.

If I were a citizen of Manitoba living with mental retardation -- This is what I would experience now:	New Direction:
- A person's limitations and handicaps are emphasized in the Individual Program Plan (IPP) assessment process, with resultant low expectations and low intensity of program. - Program planning consists largely of attempting to fit individual into existing program "slots".	- Individual and community strengths identified. - Setting goals with individual and advocates in conjunction with planning team. - Mandatory annual review by regional authority, which has the capacity to trigger new resources. - Reevaluation as needed based on plan for individual, not at arbitrary intervals. - A balance of supports and new challenges. - Supports appeal process by person, advocate, family.

Principle 2

Individual Service Planning: To support individuals with mental handicaps adequately and appropriately, it is necessary to plan, develop, improve, deliver and co-ordinate services, programs and opportunities on the basis of the strengths and needs of each individual. Such a process ensures that the supports required by an individual are available when required, that new supports are developed as needed by individuals, that funds are allocated on the basis of responding to known needs. Appropriate staff and volunteers must be trained and available to provide supports.

If I were a citizen of Manitoba living with mental retardation -- This is what I would experience now:	New Direction:
- Services which are facility, building, or "program" oriented. - Funding based on generalized minimums or lowest common denominator. - Authority lying with Provincial Community Services.	- Services which are person oriented or "individualized". - Funding based on <u>plan</u> for the person. - Authority lying with Regional Community Board with input from the person, the family, and advocates, with monitoring by Provincial Community Services, and a process for appeal.

Principle 3

Regional Resource Planning: Individual service plans are the basis for planning regional services. The creation, modification and rationalization of services is determined by clear knowledge of what individuals require and the success of services in promoting growth and development.

Regional Boards and Community Living Corporations are proposed as the mechanisms by which individual service plans are developed and implemented, regional resources are planned and developed, existing services are improved, and manpower and financial resources are developed and allocated - all firmly linked to the known requirements of individuals within the region.

If I were a citizen of Manitoba living with mental retardation --	
This is what I would experience now:	New Direction:
- Unempowered Regional liaison committees (one or two out of eight regions). - Planning based on empty beds or seats.	- Regional authority and responsibility based with citizen Board. - Planning based on individual need.

Principle 4

Community Capabilities and Responsibilities: To develop and implement individual service plans requires a systematic approach. To develop and implement regional resource plans based on individual requirements requires the capability at the community level to co-ordinate existing services, develop new resources, and ensure that services provide supports in an appropriate manner.

At the current time, there is insufficient capacity in Manitoba to determine what individuals require, develop plans on that information, support individual strength and needs once identified, or develop supports that are required but do not currently exist.

If I were a citizen of Manitoba living with mental retardation -- This is what I would experience now:	New Direction:
- No capacity to plan for individuals past facility-based service. - If the service fails, person goes to institution.	- Capacity for a community to respond to individual need, based on citizen involvement with handicapped person. - Community can respond with a variety of options.

Principle 5

Use of Generic Service Systems: There should be a planned shift in provision of services from "mental retardation specific" structures to services which are used by the general public. As a minor example, generic recreation services should be helped to accommodate persons with mental retardation rather than "special" recreation being developed. Similar shifts should occur in the provision of housing, employment, personal care and protection, adult education and income maintenance.

If I were a citizen of Manitoba living with mental retardation -- This is what I would experience now:	New Direction:
"Special Services" - Employment supports provided by vocational rehabilitation services. - Respite provided by Mental Retardation Services. - Training in residence or workshop. - Make-work projects. - Segregated recreation. - Infant development services by Mental Retardation Directorate.	Department of Labour and C.E.I.C. Home care in Department of Community Services. Adult education in Department of Education. New Careers; Career Resource Centre; Department of Labour. Municipal and Provincial Recreation Departments. Education or Public Health.

Principle 6

Deinstitutionalization

There must be an explicit policy of eliminating new admissions to institutions through the development of individual service responses plus a planned return of institutional residents to competent community based settings. We can point to other jurisdictions where this has occurred on a systematic basis.

If I were a citizen of Manitoba living with mental retardation -- This is what I would experience now:	New Direction:
- Institution is the only alternative in community crisis. - Institutionalization is used as a threat if behaviour a problem. - No planned return to community.	- Crisis intervention at community level. - Assessment of needs of current institutionalized population. - Plan which determines order of return to community and triggers appropriate service design.

Principle 7

Legal Basis: Legislation should reflect a perception of mentally retarded people as citizens with human, civil and legal rights.

If I were a citizen of Manitoba living with mental retardation -- This is what I would experience now:	New Direction:
- Orders of Supervision by one psychiatrist or two medical practioners. - No decertification process. - Control over total individual and property rights.	- Due process in courts. - Review and appeal process for decertification. - Limited control of individual rights or property based on specific assessment of need with appeal process for a safeguard.

SECTION 1 - PLANNING AND ORGANIZATION

New responsive systems seldom evolve naturally from existing and established systems.

STATEMENT OF PRINCIPLES

The foremost goal of any human service system should be to support the valued inclusion of disabled individuals in natural settings and support systems (families, schools, communities, work and social settings). The human service system should strive to eliminate or reduce disabilities and their adverse effects, and to increase the independence and quality of life experienced by the handicapped person and to develop the natural support system that surrounds him. To achieve this, the service system must, as far as possible:

- a) Work to maintain or integrate each disabled individual into natural support systems and to increase the ability and confidence of those support systems to reduce, cope with and tolerate disability.
- b) Establish a full range of service options in the individual's home community, by offering sufficient and flexible levels of assistance to natural support systems. If those systems are absent or unable to cope, new systems must be devised that are as close to what is typical and valued as possible (e.g., provision of supported foster care for children whose families cannot be assisted to meet their needs).
- c) Maintain an individual's connection to the community by assessing and responding to the capacity of natural settings and support systems to assist the person, and by systematically increasing the capacity of generic services to meet a wide range of needs.

To achieve these goals, the system must have certain characteristics:

- 1) The values of the system must be stated, and must be clearly supported in practice (e.g., if one of the system's values is to support the presence and participation of disabled individuals in the natural community, then the first and last line of defense for handicapped children should be support to natural and foster families).
- 2) The response of the system must be flexible, rapid, and based on the nature and severity of individuals' disabilities and the capacity of their natural support systems to assist them. Thus, rather than attempting to establish a comprehensive range of residential, vocational, educational and personal support

"programs" or "slots" (and then attempt to fit people into existing "slots"), the system must have the capacity to deliver funding, equipment, training, technical support or direct assistance in the individual's natural environment, or, in some instances, to provide a substitute support system.

- 3) To ensure rapid response, planning, direction and control of local resources should be vested with regionalized authorities with accountability provided by Provincial authorities.
- 4) Assessment of individual needs and recommendations for service response should be provided by a body which does not have a vested interest in controlling access to services. In this way, any "shortfalls" in the actual service response can be systematically registered and dealt with by local, regional and Provincial planning processes.

THE CURRENT SITUATION

At the present time in Manitoba, local and regional service development is controlled by a centralized directorate, and is severely limited by a massive financial commitment to institutional services which are not within the control of local service regions. Waiting lists for residential and vocational services are years long, and do not include the people who have simply abandoned hope, or have been written off as "hopeless".

Community service workers have virtually no capacity to create the specific service options required by individuals and families, and at the same time are often required to provide legal "supervision" of and representation for individuals and their estates through delegated Orders of Supervision.

Recently, a National Task Force on Community Living, sponsored by the National Institute on Mental Retardation, completed a year-long series of site visits throughout North America to document the development of community-based services. The Task Force discovered settings where entire service systems had made the shift from an institutional to a community "base" for services. For example, the Holyoke-Chicopee area of Massachusetts (population: 750,000) has returned all but 100 of its retarded citizens to community life from institutional settings, and plans are in place to move the final 100. This area has had no admissions of children to institutions for the past seven years.

The Vocational Rehabilitation Services system in the State of California has undergone dramatic shifts in the direction of natural-environment employment services during a period when the Rehabilitation budget was being reduced by one-third. A commitment to innovation, a flexible funding structure around individuals, and an alliance with consumer groups combined to generate major positive developments in a period of economic recession.

Several initiatives in Ontario and British Columbia have demonstrated that children with very complex care needs can be returned to community living, and can benefit from involvement with families, schools, and non-handicapped peers and neighbours.

Recent voluntary sector initiatives in Manitoba have shown that innovative education, housing, family support and employment services can be provided through existing generic structures, and can insure that those structures include and adapt to the needs of citizens with mental retardation.

RECOMMENDATIONS

- 1) THAT THE GOVERNMENT ESTABLISH MECHANISMS FOR TRANSFERRING THE AUTHORITY FOR DELIVERY OF SERVICES TO PEOPLE WITH MENTAL RETARDATION AND THEIR FAMILIES FROM A CENTRALIZED, BUREAUCRACY-BASED SYSTEM TO REGIONALIZED, CITIZEN-BASED, EMPOWERED PLANNING AND SERVICE DELIVERY STRUCTURES. These regional citizen boards should have both the authority and responsibility to deliver the full range of community services to people from their region. They should have full authority to contract for services with both generic and disability-specific service providers, to establish new services based on the assessed needs of individuals or communities, to discontinue the use of services no longer required, and to transfer individuals from the institution to the community. In Manitoba, school divisions, children's aid societies, and district health systems are examples of arrangements in which citizen boards are empowered to deliver a range of services in a geographic region with government acting in a monitoring and support capacity.
- 2) THAT THE REGIONAL MENTAL RETARDATION SERVICE BOARDS BE EMPOWERED TO ASSIST AND PROMOTE THE DEVELOPMENT OF CITIZEN-BASED SERVICES FOR THE PROVISION OF ASSESSMENT, SERVICE COORDINATION, RESIDENTIAL, VOCATIONAL, FAMILY SUPPORT, PROTECTION AND ADVOCACY, AND ANCILLARY SERVICES. THAT THE BOARD STRUCTURES OF ALL NEW SERVICES INCLUDE PRIMARY CONSUMERS OR THEIR ADVOCATE/ REPRESENTATIVES AND MEMBERS OF THE PUBLIC.

- 3) THAT THE EXPLICIT VALUES OF THE SYSTEM INCLUDE THE FOLLOWING COMMITMENTS:
 - a) TO ENSURE THE COMMUNITY PRESENCE AND PARTICIPATION OF ALL CITIZENS WITH MENTAL RETARDATION:
 - b) TO ASSIST EACH INDIVIDUAL WHO IS MENTALLY RETARDED TO OBTAIN LIFE CONDITIONS AT LEAST AS GOOD AS THOSE OF AVERAGE CITIZENS, AND AS MUCH AS POSSIBLE TO ENHANCE AND SUPPORT THEIR STATUS, SKILLS, RELATIONSHIPS WITH VALUED CITIZENS, AND PUBLIC IMAGE.
 - c) TO SUPPORT THE COMPETENCE AND CONFIDENCE OF NATURAL SOCIAL SYSTEMS AND GENERIC SERVICES TO INCLUDE AND MEET THE NEEDS OF ALL CITIZENS WITH MENTAL RETARDATION.
 - d) TO ENSURE PUBLIC ACCOUNTABILITY OF THE SYSTEM AND TO ENSURE PARTICIPATION OF CONSUMERS IN THE PLANNING, ORGANIZATION AND GOVERNANCE OF SERVICES.
- 4) THAT THE GOVERNMENT ESTABLISH A POLICY OF SHIFTING SERVICE DELIVERY FROM DISABILITY-SPECIFIC (mental retardation) TO GENERIC SERVICES AND AUTHORITIES - systems which are universally available to all citizens. Just as provision of education for handicapped children has shifted from mental retardation to public education auspices, so housing, employment, adult education, home care, protective and social services should be provided under generic auspices, with the assistance of (and at times under contract with) the regional authorities mentioned in Recommendation (1) above. Existing disability-specific service providers - group homes, workshops, etc. - would continue to operate under contract with the regional boards, but may be gradually replaced through a shift to generic services.
- 5) THAT EACH REGIONAL BOARD BE MANDATED TO PHASE OUT THE USE OF TOTAL INSTITUTIONS BY SIMULTANEOUSLY:
 - a) Developing individual community support responses for individuals seeking or considered for institutional admission.
 - b) Moving current institutional clients to the community by devising individual housing, developmental, employment and personal support arrangements for a predetermined number of people each year. (One jurisdiction dealt with the problem of achieving fairness in this process by assigning future discharge dates to all institutional residents on a lottery basis, and then insuring that communities received the planning and service delivery resources required to meet those commitments.)

- c) Providing communities (regional boards) with the ability to recover institutional per diem rates when institutionalized residents are returned to approved community living arrangements. This recommendation would require that the central government provide financial subsidies to institutions as their populations decline, in order to cover fixed costs which will continue for some time, and to improve living conditions for residents who remain in institutions awaiting community living arrangements.
- 6) THAT FUNDING FOR INDIVIDUAL SERVICE ARRANGEMENTS BE ATTACHED TO THE INDIVIDUAL CONSUMER (ideally, using Social Allowance and Child Welfare, rather than Mental Retardation funding mechanisms), and
- 7) THAT INDIVIDUAL FUNDING BE CONSIDERED "PORTABLE", SO THAT THE REGIONAL AUTHORITY HAS THE ABILITY TO MOVE A CONTRACT FOR INDIVIDUAL SERVICE FROM ONE PROVIDER TO ANOTHER.
- 8) THAT THE GOVERNMENT ESTABLISH A STANDARD OF LIVING FOR PEOPLE WITH DEVELOPMENTAL SPECIAL NEEDS THAT IS ABOVE THE POVERTY LINE FOR MANITOBIANS. This stands in sharp contrast to the current practice of maintaining mentally retarded citizens at "basic welfare levels" -- a practice which adds the stigma and disabling effects of poverty to that of mental retardation.
- 9) THAT PROVINCIAL COMMUNITY SERVICES PROVIDE OVERALL MONITORING OF THE PERFORMANCE OF THE SERVICE SYSTEM AT A REGIONAL LEVEL. A similar relationship exists between the Director of Child Welfare and regional Children's Aid Societies, and between the Department of Education and local school divisions.
- 10) THAT THE PROVINCE RETAIN DIRECT RESPONSIBILITY FOR OPERATION OF THE MANITOBA SCHOOL AT PORTAGE LA PRAIRIE.
- 11) THAT THE MINISTER OF COMMUNITY SERVICES AND CORRECTIONS ESTABLISH A PLANNING COMMITTEE CONSISTING OF THE MINISTER OF COMMUNITY SERVICES, THE PRESIDENT OF THE MANITOBA DIVISION OF C.A.M.R., AN M.L.A. (without portfolio) APPOINTED BY THE PREMIER, THE CHAIRPERSON OF THE GOVERNMENT'S SOCIAL POLICY COMMITTEE, AND A PARENT APPOINTED BY THE SOCIAL POLICY COMMITTEE TO PREPARE AN INITIAL PLAN FOR IMPLEMENTATION OF THE RECOMMENDATIONS CONTAINED IN THIS SECTION OF THE REPORT (and related recommendations from other sections) WITHIN FOUR MONTHS OF FORMATION OF THAT COMMITTEE. One specific role of that committee would be to detail the relationship of the recommended regional mental retardation service boards to other government bodies such as the Residential Standards and Licensing Branch, Agency Relations Branch, the Public Trustee, Program Analysis and Review Branch, the Child Welfare Directorate, Office of Continuing Care, Income Security, and other generic service divisions of government.

The Planning Committee should develop plans to ensure and support implementation of the community-based Regional Boards. They should plan to supply appropriate technical support and training to community-based Regional Boards. A province-wide strategy for manpower development should be undertaken (which includes professional and volunteer education).

SECTION 2 - LEGISLATION AND LEGAL AUTHORITY

STATEMENT OF PRINCIPLES

To change significantly the direction of service development for people who live with mental retardation we require a new Act that:

- states clear intention to make policy, planning and service development take place,
- is based on the premise that mentally retarded people are citizens with human, civil and legal rights,
- is written in a style and format that persons with mental retardation, families with members with mental retardation and the public can read and understand,
- addresses guardianship with a perception of citizens with mental retardation as developing human beings,
- creates, by legislation, the regionalized service delivery boards based on consumer and citizen participation, for the planning and operation of future mental retardation services.

RECOMMENDATION

- 1) THAT THE ATTORNEY GENERAL OF THE GOVERNMENT OF MANITOBA INITIATE A PROCESS FOR REPLACEMENT OF THE CURRENT MENTAL RETARDATION SECTIONS OF THE MENTAL HEALTH ACT WITH A NEW ACT BASED ON THE ABOVE-MENTIONED PRINCIPLES.

THE CURRENT SITUATION

Inadequate Safeguards

Most people with mental retardation have difficulty representing their own interests. Many grow up without opportunities and support for making judgements and speaking up for themselves. Many have difficulty figuring out complex situations and making sensible judgements about them. Some are particularly handicapped by a service system's incompetence to remedy a communication problem and literally can not say what they think. A few are so handicapped that they seem to us unable to represent themselves in any but the most immediate situation, if at all. But, all people with mental retardation also face generations of prejudice: prejudice that has justified their isolation from community life in institutions; prejudice that has portrayed them as a menace to their communities and themselves; prejudice that has supported a policy of minimizing community investment in supporting their growth and development; prejudice that teaches people with mental retardation, and even their families, that

they have nothing to say, and that if they do speak up, they will only prove their foolishness and anger their keepers. These prejudices create an oppressive culture of silence - a culture in which most people with mental retardation in Manitoba have grown up.

We are concerned because we think that the interests of people with mental retardation are poorly protected in Manitoba. We believe that necessary safeguards are missing and that the major mechanism for personal protection -- the use of Orders of Supervision -- is based on prejudiced beliefs and actually results in harmful treatment of those it should protect.

Orders of Supervision

Manitoba's Mental Health Act (1974) empowers the Director of Psychiatric Services to place people with mental retardation in institutions or "under supervision under such terms and conditions as he sees fit". (31 (1)). When a person who is mentally retarded is placed in an institution or under supervision, the Director of Psychiatric Services may:

... at any time, where he considers it to be in the interests of the mental retardate (sic) or the public,

- (1) direct that the mental retardate (sic) be discharged from the institution either conditionally or unconditionally; or
- (2) direct that the mental retardate (sic) be granted temporary leave for such period of time as he considers reasonable; or
- (3) OTHERWISE DEAL WITH THE MENTAL RETARDATE (sic) AS HE SEES FIT. (Emphasis added). (39 (1)).

Further,

... an order made by the director under subsection (1) (above) may be rescinded by him; and he may, by further order, direct that the mental retardate (sic) be retaken and again placed in an institution or under supervision. (39 (2)).

The Director of Psychiatric Services is apparently able to delegate these powers in writing to "any suitably qualified person". (4 (1) (g)) and "has, and may exercise the powers of a magistrate for the purpose of enforcing any of the provisions (of the part of the Act dealing with people with mental retardation)". The director's decisions on placement or orders of supervision can be appealed to "The Ministers Board" -- a board appointed by the Lieutenant Governor in Council. This board has never been appointed.

People who are institutionalized, or who leave institutions, or who are under orders of supervision must have a committee (guardian) of property and person. Where the court has not appointed a committee,

the provincial Public Trustee acts as committee of the estate and of the person (79 (1)).

Within Manitoba, a substantial number of people are under Orders of Supervision. Supervision is delegated by the Director of Psychiatric Services to the Regional Director, Department of Community Services and Corrections. The Regional Director in turn delegates administration of the Order, typically to the community service workers assigned to the area where the person lives, but occasionally to others.

There are several major problems with this approach to providing people with mental retardation with personal protection.

- The act gives the Director of Psychiatric Services power over people's lives which we believe is without parallel in modern law pertaining to people with handicaps. It offers no guidance or restraint except the director's own judgement, and explicitly vests him with judicial and police powers. It provides no check on the exercise of his power except limited recourse to a politically appointed board, which does not and has never existed.
- The act is excessively restrictive. It calls for every person under an Order of Supervision to have both a committee of the estate and a committee of the person.
- Its purpose is much less the protection of the person and provision for representing his or her interests in a better quality of life than it is protection of supposed community interests. The act is full of procedural detail but makes no statements to guide those who act on behalf of a person to consider and represent his interests.
- The act is poorly drawn. It is confusing in its language and in its layout.
- As administered, the act is rife with conflict of interest. Orders of Supervision are frequently imposed by the Director of Community Mental Retardation Services acting as designee for the Director of Psychiatric Services. Supervision is routinely assigned to government employees who are responsible for administration and providing essential services. In at least one instance, a Regional Director has taken the further step of delegating Orders of Supervision to the staff of a residential service.
- The act results in preoccupation with control on the part of many who administer Orders of Supervision. Relationships with service workers are placed upside down. Instead of forming relationships based on positive alliances for promoting growth and development, relationships are based on control of the person with mental retardation. The person with mental

retardation must please the worker or face the threat of reinstitutionalization, or being moved, or having controls placed on his money or his movements.

- The act creates a belief that the service system and its workers are, by themselves, a sufficient safeguard for people's interests. This is not only a false idea, it doesn't work in practice. For example, people under Orders of Supervision have been placed by vocational counsellors in work settings (regular industry) that are based on exploiting people with mental handicaps by underpaying them. Those responsible to protect these people have apparently participated in keeping people at work under these unjust conditions. Other people under Orders of Supervision have needs for medical and dental care which are going unmet, apparently for lack of vigorous personal representation.
- The act as administered results in de-individualization. For example, in one instance irresponsible behavior by one person led to a change in everyone's conditions of Supervision.
- The act as administered results in substantial overprotection. Many people could become far better able to make appropriate judgements if service workers taught more and controlled less, and if people with mental retardation had the opportunity to make personal decisions without the threat of institutionalization.
- The act as administered is unfair. While Regional staff have made efforts to remove Orders of Supervision from a number of people, we can discover no rhyme or reason to why some people are under Orders and others are not. This unfairness falls especially heavily on people who have become separated from their families, and thus depend completely on service system employees to speak up for them.
- The act has a powerful negative impact on the interpretation of people with mental retardation.
 - * The entire act lumps mental retardation with unrelated "mental health problems".
 - * By requiring a physician's certificate, it treats the issue of whether a person needs guardianship or extra social support as if it were a medical matter.
 - * It defines "a mental retardate" (itself a demeaning term) in circular fashion as a person who "needs supervision", "for the protection or welfare of the person or others".

SECTION 3 - FAMILY SUPPORT AND CHILDREN'S SERVICES

STATEMENT OF PRINCIPLES

Services for children who have mental and physical handicaps must be founded on a clearly articulated and shared value base which recognizes the children as developing human beings whose legal and human rights must be safeguarded. These children have the right to be welcomed by and included in society, to live with dignity in their own communities and, to receive (as do their families) the assistance and support necessary to meet their needs.

It is our fundamental belief that the needs of any child (including children who need special assistance) can best be met within the context of a loving, adequately supported family. Every child needs to experience the sense of belonging and acceptance, the security of consistent caregivers, the individual attention and the intimate relationships which are most naturally and fully provided in a family - preferably his family of origin, but if this is not possible, another family.

Every child has the right to full membership in society and the community. This begins with membership in a family and, through the family, membership and interaction with friends and neighbours in the larger community.

An Appropriate Service Design:

- Ensures that children have the opportunity to grow up in a family, and supports all efforts of the natural family to keep their children at home.
- Offers families the information, assistance and practical supports necessary to maintain their confidence and ability to meet the needs of their child within the family unit and to maximize the child's learning environment and learning opportunities.
- Fosters positive interpretations and expectations related to both the child and the family and does not stigmatize the child and family; and is as non-intrusive as possible.
- Represents the rights and interests of children and their families; actively encourages and provides the means for the family to achieve and retain autonomy in planning and decision making in the best interests of the child.
- Strengthens or re-establishes the child's and family's network of personal and community support; encourages and supports the child and family in participation and membership in a wide range of community activities.

- Increases the involvement and ability of generic services to respond to the needs of the children and their families.
- Assists parents to make the best possible use of existing services, particularly generic services (daycare, early education programs, public health nursing, medical services, physiotherapy, occupational therapy etc.) by providing information, linkage, funding where necessary and follow-up.
- Broadens the base of community support available to the child and family by creating opportunities for alliance and assistance from extended family, neighbours and friends.
- Strengthens the political effectiveness of parents and advocates for the child.
- Ensures that the child's need for nurturing relationships and specific developmental encouragement is met in the most natural and enhancing way possible and that specialized services (eg. physiotherapy) are available as required.
- Demonstrates that children with high support needs can live with dignity in their own communities.
- Finds families for children who cannot live with their natural families and for children who currently reside in institutions. In the event that a child must live apart from his family, encourages close contact between the child and his natural family, facilitates participation by the natural family in decisions affecting the child and whenever possible, allows the natural family to retain guardianship.
- Is characterized by a commitment to learn from the experiences of individual children and their families and the capacity and flexibility to modify its response accordingly.
- Has the capacity to ensure individual advocacy.

THE CURRENT SITUATION

On an individual basis families often find themselves:

- made to feel incapable of meeting the specific developmental needs of their children;
- denied the types and amounts of practical supports required to meet the needs of their children and thus discouraged from keeping them at home;

- intimidated by and deferring to professional caregivers;
- denied power and opportunities to influence the development and provision of services to their children;
- forced to make choices among service options without full knowledge of potential community alternatives, and without knowing the intended and unintended (and often harmful) effects of proposed services on the child and family.

Families may require substantial supports - back-up caregivers for periods when they are unable to be with the child, transportation, integrated developmental and educational services, physiotherapy, information and advice, advocacy, and the presence of a supportive network of friends, neighbours and relatives. Unfortunately, families who wish to keep their children at home are confronted with disincentives and are discouraged and disabled by a lack of practical and moral support. Always, our first line of advocacy is to support the natural family in keeping the child within the family unit.

However, due to inadequate services to families, and at times due to problems arising within the family, there are many families who find themselves unable to continue caring for their children in their own homes. This may be for a short period of time, but is more likely to be seen as a long-term need. A number of Manitoba children are currently awaiting institutional or group placement.

In addition to children at risk of institutionalization, a number of children live in institutions or group homes. Some have been separated from their families for years; some are temporary or permanent wards of the Crown; others retain close contact with their families. Many families whose children are in institutions would prefer to see their children in the community. They are, however, reluctant to press for community placement because they know the necessary services do not exist.

Although there are a number of children with mental and/or physical handicaps who currently reside in foster homes, the pace of development of additional support homes has been exceedingly slow. Service providers and families have been reluctant to consider placing children with high support needs into foster homes, and families have not come forth in great numbers to offer their homes to such children. This reluctance has been attributed to the extensive needs of the children or to the unwillingness or inability of families to support handicapped children. There is an assumption on the part of service workers that potential foster families are unwilling to support children with complex needs.

In spite of these assumptions, there is ample evidence that children who present a significant challenge to families and

communities can be cared for in regular families if adequate supports are provided. We can draw on examples of services which have been organized to do this very thing - and which are working (See Appendix I).

Case Management

Workers have found it necessary to build elaborate support systems around individual children and families in a context in which required services come from many different sources, where stringent criteria may exclude children from eligibility for service, and where some essential services are not available or are not of the intensity which the child requires. The task of arranging services to meet the needs of the child and family becomes the responsibility of busy case managers, or in many instances, the family itself.

Control

Manitoba's Mental Health Act confers upon the Director of Psychiatric Services (in practice upon the Director of Mental Retardation Services), an inordinate amount of power to control decision-making in the lives of children who have mental handicaps and their families. This power is delegated through the Regional Director to community service workers. Their role often becomes one of attempting to limit service in accordance with policies issued by the Mental Retardation Directorate - often channelling children into segregated settings. Directive #4 (based in the Mental Health Act and the Child Welfare Act) requires that the Director of Psychiatric Services request the Director of Child Welfare to assume supervision of a child labelled "mentally retarded" if the child's parents request that he be placed with another family, but wish to retain guardianship. The Director of Psychiatric Services is thus in a position to recommend a particular service response, and frequently recommends placement in an institution.

The current emphasis on disability-specific services rather than generic services (those legally available to all citizens - Public Health, Continuing Care, etc.) results in children being denied the services which everyone else has a right to and causes children to be labelled and stigmatized in order to receive services. Generic services are not given the mandate or the resources to meet the needs of individuals who are labelled mentally retarded.

RECOMMENDATIONS

- 1) THAT THE MINISTER OF COMMUNITY SERVICES ESTABLISH POLICY FOR SERVICES TO CHILDREN WITH MENTAL RETARDATION WHICH INCORPORATES AND IMPLEMENTS THE PRINCIPLES OF SERVICE DESIGN OUTLINED ABOVE.

- 2) AS INDICATED IN THE SECTION ON "PLANNING AND ORGANIZATION," THAT THE MINISTER OF COMMUNITY SERVICES CREATE AND MANDATE EMPOWERED COMMUNITY OR REGIONAL BOARDS COMPOSED OF CONSUMERS OF SERVICE AND THEIR ADVOCATES, PARENTS (IN THE CASE OF CHILDREN), AND CITIZENS. These boards should have the authority for planning, implementing and co-ordinating services to children who have mental and physical handicaps and their families.

They would control funding and have the power to contract with existing generic services.

- 3) THAT FAMILY SUPPORT SERVICES BE UNDER THE DIRECTION OF THESE REGIONAL COMMUNITY BOARDS, WHICH WOULD HAVE THE POWER TO OVERSEE AND/OR CONTRACT WITH OTHER AGENCIES FOR SERVICES,

- A. THAT INFANT DEVELOPMENT SERVICES FOR CHILDREN AGES 0 - 3 YEARS BE DELIVERED BY GENERIC SOURCES (eg. PUBLIC HEALTH NURSING) AND THAT ADDITIONAL FUNDS BE EARMARKED TO HIRE STAFF TO DIRECT AND CO-ORDINATE THESE EFFORTS.

Parents should also be allowed the option and funding to create infant development co-operatives, if they so choose, to serve specific communities or geographical areas.

- B. THAT RESPIRE SERVICES (BACK-UP CAREGIVERS) BE CONTROLLED BY AND CONTRACTED FOR BY COMMUNITY BOARDS (THESE SERVICES COULD COME THROUGH CONTINUING CARE). FAMILIES SHOULD BE ALLOWED THE OPTION TO CREATE RESPIRE CO-OPERATIVES, FUNDED BY THE GOVERNMENT. FAMILIES SHOULD BE ALLOWED AS MUCH RESPIRE TIME AS THEY ACTUALLY REQUIRE, WHEN THEY REQUIRE IT.
- C. THAT PAID TRANSPORTATION TO GENERIC INTEGRATED DAY CARE CENTRES, NURSERY SCHOOLS, RECREATIONAL AND EDUCATIONAL PROGRAMS BE PROVIDED AS NEEDED.
- D. THAT EXISTING FINANCIAL SUPPORTS TO GENERIC DAY CARE CENTRES AND LUNCH AND AFTER SCHOOL PROGRAMS BE CONTINUED AND EXTENDED.
- E. THAT FAMILIES BE PROVIDED WITH DIRECT FINANCIAL SUBSIDIES FOR SPECIAL NEEDS AND EQUIPMENT.

- 4) THAT LEGISLATION ESTABLISH MANDATED INDEPENDENT INDIVIDUAL ADVOCACY SERVICES FOR CHILDREN AND THEIR FAMILIES AND THAT THIS ADVOCACY BE VESTED IN A BODY OUTSIDE THE SERVICE MANAGEMENT ROLE (See Appendix IV).

- 5) THAT THE MINISTER OF COMMUNITY SERVICES COMMISSION AN INDEPENDENT ASSESSMENT OF EACH CHILD CURRENTLY LIVING AT THE MANITOBA SCHOOL AND ST. AMANT CENTRE AND THOSE LIVING IN GROUP HOMES TO DETERMINE WHAT SPECIFIC SUPPORTS WOULD BE REQUIRED TO MEET EACH CHILD'S NEEDS WITHIN A FAMILY IN THE COMMUNITY.

- 6)
 - A. THAT BY APRIL 1985 ALL ADMISSIONS TO THE ST. AMANT CENTRE AND MANITOBA SCHOOL CEASE.
 - B. THAT EACH CHILD ON THE WAITING LIST FOR ST. AMANT BE ASSESSED TO DETERMINE WHAT SPECIFIC SUPPORTS HE/SHE WOULD REQUIRE TO LIVE COMFORTABLY WITH HIS OWN FAMILY, WITH ANOTHER FAMILY OR A FAMILY-LIKE HOME SETTING.
 - C. THAT COMMUNITY BOARDS BE GIVEN THE RESOURCES TO DELIVER THESE SUPPORTS.
- 7) THAT THE CHILD WELFARE ACT AND THE MENTAL HEALTH ACT BE MODIFIED SO THAT DIRECTIVE #4 IS ELIMINATED. THE DIRECTOR OF CHILD WELFARE SHOULD HAVE THE POWER TO ASSUME PLACEMENT RESPONSIBILITY ON A LONG-TERM BASIS AT THE PARENTS' REQUEST WITHOUT INSTRUCTION FROM THE DIRECTOR OF PSYCHIATRIC SERVICES.

SECTION 4 - EDUCATION

STATEMENT OF PRINCIPLES

This section will address four major issues in education services:

- 1) quality of education;
- 2) physical and social integration;
- 3) a child's connections with family and community;
- 4) due process.

The Quality of Education

Curricula, staffing levels and teaching techniques must be designed to support learning which is relevant to individual needs and directed towards developing real competencies. Challenge, intensity and reasonable but high expectations are necessary features of such education.

Students who need support beyond those typically provided for all students must have individual written education plans which are based on an assessment of educational needs, which specify the goals or competencies to be achieved, which have an explicit time frame, and which are designed to keep the students in regular settings or return them to a regular setting within a specified period of time.

Physical and Social Integration

For students who have handicaps, ongoing integration with non-handicapped peers is essential to intellectual and social development. Friendship, stimulation and opportunities to learn by modelling the behaviour of others are readily available in integrated settings. Children who are included in the regular educational milieu are much more likely to be seen as full members in society and are more likely to develop the competencies and social skills which facilitate inclusion when they become adults.

The law should be explicit in the intent that students be assimilated into regular educational settings and activities, and whenever possible, into regular classrooms which are age-appropriate (a good example of this concept in action is Lord Roberts School in Winnipeg). In a similar vein, barrier-free design of all school buildings would facilitate physical integration, which is a pre-requisite to social integration.

A Child's Connections with Family and Community

Each school division has the ultimate responsibility for the education of all children who live within its borders. A child who attends a school in his/her own neighbourhood enjoys several distinct advantages: 1) his/her schoolmates are likely to become after-school friends, 2) extra-curricular activities are encouraged; and 3) short trips to and from school allow a longer learning day. Parents have more opportunity to provide input and support to a school in their home division, particularly one located in their neighbourhood.

Legislation must explicitly address each division's responsibility to its own children and create strong incentives, in the form of fiscal and program supports, for each division to meet the needs of its children rather than send them out of their division. As the legislation stands, divisions which have developed resources are likely to be overwhelmed with referrals. Other divisions are not explicitly encouraged to develop the organization and supports required if children are to be served in local schools.

Any plan to send a child out of the division should be subject to Ministerial approval and review and be contingent upon the submission by the home division of a plan to meet the needs of the child in his/her home division within an explicit time frame.

Due Process

Parents and guardians and students themselves should have the right to participate in decisions affecting their education. This requires:

- a) that students and parents have access to the information on which such decisions are based, including school and assessment records,
- b) the establishment of a mechanism whereby students or their parents/guardians may appeal the student's placement and education plan. Such a mechanism should be explicitly outlined and established in legislation. An internal appeal might proceed to the school board of the home division and then to the Minister and be supported by the establishment of an educational ombudsman. An external appeal process should be established, which would permit appeal through the judicial system.

THE CURRENT SITUATION

- The high degree of emphasis on program and content rather than student's needs at the post-elementary level cause problems for certain students with special needs.

- Policies and practices which isolate and segregate certain students and thus stigmatize them and inadequately prepare them for living in a real world.
- Physical design limitations which prevent access for certain students, thus limiting their effective integration.
- Teacher training which typically does not emphasize collaboration among a resource team charged with meeting special learning needs of students.
- Class size, case load and expanding curricula which cause educators to have inadequate time and resources to monitor individual student needs, to differentiate instruction, and to spend the time needed to develop mastery in all students.
- The persistent perception of many teachers and others that "difference" is synonymous with a value judgement and is usually negative, leading to inappropriate labelling and treatment.

RECOMMENDATIONS

To accommodate the stated concerns, we offer the following recommendations regarding the Education Act.

1) TO SECTION 41 (4) SHOULD BE ADDED:

Every child shall be educated in the most typical and integrated setting possible. All students shall be assimilated into regular education settings and activities, and whenever possible into regular classrooms which are age-appropriate. Any plan to educate a child in other than an integrated classroom in a regular school will be contingent upon the approval of the superintendent and a written individual education plan which specifies the goals and competencies to be achieved, the areas in which the student will remain integrated while receiving specialized instruction, and the plan to return him/her to a regular setting within a specified period of time.

Curricula, staffing levels and teaching techniques shall be designed to support learning which is appropriate to individual needs, and which challenges and assists students to develop increasing competencies. Students who need supports beyond those typically provided for all students must have an individual written education plan which is based on an assessment of educational needs, which specifies the goals or competencies to be achieved, which has an explicit time frame and which is designed to keep the student in a regular setting or return him/her to a regular setting within a specified period of time.

2) TO SECTION 41 (5) SHOULD BE ADDED:

Any plan to send a child out of his/her school division will be subject to Ministerial approval and be contingent upon the submission by the home division of a plan for meeting the needs of the child in his/her home division within a specified time frame.

3) TO SECTION 43 (1) SHOULD BE ADDED:

...or for pupils who cannot walk to school due to physical or functional impairment.

4) That a new section should be introduced dealing with the right of students or their parents or guardians to participate in decisions affecting their education and to appeal decisions regarding placement and programming. Such a clause should be inserted prior to the sections regarding the rights of teachers and school boards. This new section, 100 (1), would read:

Any student or his/her parent or guardian may appeal a decision regarding his/her placement or educational plan. Such an appeal must be entertained by the home school division's board, and if not resolved, proceed to the Minister. The system of appeal shall be supported by an educational ombudsman, and shall include the right of final appeal through the judicial system.

Regarding instruction in public institutions:

5) SECTION 206 SHOULD BE AMENDED TO READ:

In the case of public institutions supported in whole or in part by the government, the minister shall provide for the educational instruction of all pupils who reside therein and shall pay the costs incidental thereto including the salary of the teacher or any part of those costs out of the moneys annually authorized by an Act of the Legislature to be so paid and applied.

Regarding responsibility to send a child to school:

6) SECTION 260 (1) SHOULD BE AMENDED TO READ:

Every parent of a child of compulsory school age and every person who has or receives a child of compulsory school age in his house or in an institution, whether that child is his own or that of any other person and the child is resident with and in the care and custody of the parent or person, as the case may be, shall ensure that the child attends school, unless specifically excused in writing by the Minister, in accordance with the provisions of this Act and the regulations.

RECOMMENDATIONS

7) NEW TECHNOLOGIES

That the Minister of Education consider the development of a "New Technologies Centre" within the Child Development and Support Services Branch. Such a centre should arrange for, or coordinate, the systematic assessment and field-testing of new technologies and should promote awareness of relevant new technologies for children with special learning needs or handicapping conditions.

8) COMMITMENT TO REMEDIATION OF DIAGNOSED HANDICAP

That, as a matter of general policy, the Department of Education ensure that appropriate resources for remediation are provided to School Divisions and a system of accountability be developed to ensure that funding is used for the specific program identified.

9) ELIGIBILITY FOR SCHOOL SERVICES

School services to children with special needs should be extended from birth to 21 years.

10) LINKS BETWEEN DEPARTMENTS

a) That the regional directors of Community Services and Corrections, and subsequently the regional community board, appoint a staff person to work cooperatively with each school division or district in the region, to facilitate the orderly provision and coordination of available resources.

b) That Education department program and funding guidelines should not prevent either Health, Community Service or Education personnel from working with children of any age who need such services in any setting.

11) THE SCHOOL SYSTEM'S RESPONSE TO THE STUDENT WITH SPECIAL LEARNING NEEDS

That the Department of Education develop a series of approaches to sensitize school divisions and teachers to the range of "system-caused problems", and to develop strategies to minimize such problems.

12) TEACHERS, TRAINING AND SPECIAL EDUCATION

That all teachers receive adequate instruction on the basic the purposes of education including:

- a) moral and ethical issues in education
- b) needs of handicapped people
- c) assessment and goal setting technique

- d) teaching methods
- e) human rights
- f) normalization

with such grounding having emphasis the practical application of these principles in the classroom setting.

- 13) THAT TEACHERS IN TRAINING BE REQUIRED TO TAKE A PRACTICUM IN SPECIAL NEEDS EDUCATION OVER AND ABOVE CURRENT FIELD EXPERIENCES.

- 14) THAT COMMUNITY COLLEGES AND/OR UNIVERSITIES ASSUME RESPONSIBILITY FOR CAREER-ORIENTED TRAINING PROGRAMS FOR MENTALLY RETARDED PERSONS.

Courses should range from general content (such as an orientation to the importance of work), to training in general work habits, to training for job-specific skills.

- 15) THAT CONTINUING EDUCATION ASSUME RESPONSIBILITY FOR PROGRAMS OFFERING PERSONAL/SOCIAL INDEPENDENCE TRAINING FOR MENTALLY RETARDED ADULTS.

Such programs should focus on life enriching, competency building courses.

- 16) A. THAT ALL SCHOOL-AGED CHILDREN RESIDING AT ST. AMANT CENTRE OR THE MANITOBA SCHOOL RECEIVE AN APPROPRIATE EDUCATION SERVICE IN LOCAL SCHOOLS, and
- B. THAT THE RESPONSIBILITY FOR FINANCING THE NEEDED SERVICES BE THAT OF THE SCHOOL DIVISION OF FAMILY ORIGIN AND THE DEPARTMENT OF EDUCATION.

SECTION 5 - EMPLOYMENT AND RELATED SERVICES

"...what we've typically done in the past with mentally retarded people is we've imposed restricted options and generalized how wide the scope of their options should be, and we've policed them to make sure that they've stayed within that narrow spectrum that we've defined for them. And, in doing so, we've channeled them very specifically into certain kinds of lifestyles. What I'm saying is that we've got to open this world up, and mentally retarded persons have to have the same options that you and I have."

John DuRand, President, Minnesota Diversified Industries
Winnipeg, 1973

STATEMENT OF PRINCIPLES

A new service system has to be designed to accommodate our new awareness of the abilities and potential of Manitoba's mentally retarded citizens.

Given that they are able to achieve meaningful participation in the economic community -- that they can be employed -- we can no longer regard their occupational needs as a "social problem" to be addressed exclusively by a social agency. Rather, recognizing their rights, needs, and abilities for employment and employment training, we must make provision for mentally retarded citizens to benefit from the economic and employment agencies available to all other citizens of this province.

Such a new service approach should be designed to promote each individual's right to:

- economic well-being and/or prosperity;
- opportunity to develop and increase a repertoire of personal skills, abilities and knowledge;
- situations where these achievements can be applied to meaningful tasks;
- a sense of personal dignity and worth.

THE CURRENT SITUATION

The adult lifestyles of the overwhelming majority of Manitoba's mentally retarded citizens are typified by experiences of impoverishment, underemployment, and near-negligible opportunities for skill development.

For the hundreds of men and women residing in our residential institutions there is almost a total lack of opportunity to earn a significant income.

Upon graduating from the educational system, mentally retarded men and women are routinely channeled into a service system which effectively dead-ends most of them into ghettoized programs which generally:

- underutilize their skills;
- offer little opportunity for skill development;
- underpay them for work performed;
- offer little or no opportunity for advancement;
- offer little chance for transition into the competitive labour market.

The limited number of "spaces" available in these programs force many hundreds more to stay at home, deprived of even the minimal benefits of these services.

Apart from this, an increasing (though minute) number of mentally retarded persons are coming into contact with the competitive labour market. They are, generally speaking, not meeting with a high degree of success. There are a number of factors involved. These include:

- individuals' lack of job-specific competencies;
- difficulty in identifying appropriate job opportunities;
- hesitation on the part of employers;
- lack of incentive programs to attract employers;
- difficulties encountered in job application processes;
- difficulties experienced by the employee during the job-adjustment period;
- lack of supports to the employer to adapt the worksite and/or job processes to the abilities of the new employee;
- inadequate follow-up and job-stabilization supports for the new employee;
- lack of adequate controls to protect the employee against exploitation.

Program: Oshawa Residential Services (Oshawa, Ontario)

One agency that responds to children and adults in a way that provides both an alternative place for children to live and the continued involvement of the natural family is Oshawa Residential Services. The program is sponsored by the Oshawa and District Association for the Mentally Retarded.

As a first line back-up to living in the family home, this agency matches the child's family with another family with whom the child can live. These "Associate Families" are recruited, trained and employed by the agency to be a second family for the children who cannot continue to live with their natural families. The matching of families, natural and "associate", is done with extreme care and either family can veto decisions at any point in the process. In-home support, professional supports, and on-going training are available to support associate families.

This program involves children living with a wide range of handicapping conditions, including children with very complex needs who historically would not be seen as capable of being supported in families, i.e. would be institutionalized.

The Oshawa Associate Families Program is a refinement of the Community Training Homes approach of the Macomb-Oaklands Regional Centre in Michigan. The MORC program supports 250 children living with 225 families (October 1981 information). The majority of these children (over 70%) have one or more medical problems requiring continued monitoring and/or treatment by health care professionals.

Program: Ceci's Homes For Children (Toronto, Ontario)

Children's group homes represent a more restrictive third-choice arrangement. The group home life-style has numerous shortcomings, although when combined with intensive developmental programs they sometimes have practical advantages. One such program is Ceci's Homes.

Ceci's Homes¹ provides supports for up to 24 children who live in four apartments located in a 72-unit co-operative complex in downtown Toronto. The children who live in the apartments have all been diagnosed as having mental retardation ("severe to profound" range) and at least one other additional handicap such as convulsive disorders, spinal deformities, blindness, deafness, and respiratory disorders.

¹ The Board of Ceci's Home regrets the congregation of six children per unit and recommends a maximum of three.

In addition to providing a quality home environment for the children, Ceci's Homes has arranged an extensive developmental program to be provided with a network of links to local schools, medical specialists, and recreation programs.

Other children's group homes which serve children who have been labelled either "medically fragile" or "severe behaviour problems" include ones in Lethbridge, Alberta; Kingston, Ontario; Harcourt, New Brunswick; and, Corner Brook, Newfoundland.

B. For Adults

Many of the residential programs for children who are severely, profoundly and multiply handicapped have been developed in support of families in crisis, to prevent the institutionalization of children in the community. Major strides are being made in both the United States and Canada to provide decent places for adults to live, often after those adults have spent a large proportion of their lives in institutions. Successful programs have been developed that support adults so they can live in normal community housing in groups as small as one with staff support.

Program: The Community Living Board (Vancouver, B.C.)

The Community Living Board developed from the concerns of parents whose sons and daughters had lived for years in institutions. To date, the CLB has assisted fifty individuals to return to the community from institutions. The agency itself helps individuals who are developmentally disabled, with the full involvement of their families and friends, to identify and secure those supports within the community that are necessary to meet the individual's on-going daily needs. The individuals assisted by the CLB live in normal community housing with no more than four individuals to a house; participate in day programs; and are actively involved in community life. Generic community services are utilized for educational, medical, and recreational support.

A number of the individuals supported by the CLB are considered to be severely or profoundly mentally and physically handicapped.

Region: The Greater Philadelphia Area

A number of residential service providers in Montgomery and Chester Counties provide small group living arrangements for individuals who formerly resided in Pennhurst, a large state-run institution in Pennsylvania. The individuals, who live in a wide variety of neighbourhoods in normal housing, are considered to be "very aggressive, autistic, severely/profoundly retarded, extremely self-abusive, non-verbal, spastic-quadruplegic-hydrocephalic, etc". All are living

This situation, although disturbing, is not surprising given the nature of the mechanisms currently used to deliver employment-related services to mentally retarded citizens.

In years past, an assumption was made that people with mental retardation were not capable of productive employment. "Occupational Activity Centres" were instituted to provide diversional activity for this unemployed segment of our adult population. This service was neither intended to provide employment nor to increase the employability of those served.

Over the years, the mentally retarded men and women in these services have demonstrated learning and performance competencies well beyond our highest levels of expectation. Indeed, even men and women considered severely and profoundly retarded have demonstrated that, given the proper training opportunities, they are capable of learning and performing complex and demanding tasks--demonstrating employability skills.

The old social service design which we have inherited has not, despite concerted effort, been able to keep pace with these changes. Frustration, discontent, and resentment are increasing as a natural consequence of ambitions and needs being thwarted and constrained by outdated and ineffective service structures.

RECOMMENDATIONS

For immediate implementation:

- 1) THAT OCCUPATIONAL ACTIVITY PROGRAMS CURRENTLY FUNDED BY VOCATIONAL REHABILITATION SERVICES (KNOWN COLLECTIVELY AS "WORKSHOPS") BE COMPREHENSIVELY REVIEWED AND REDESIGNED.

New program definitions, standards of service, and funding schedules must be developed in the following three areas:

EMPLOYMENT - programs designed to provide "sheltered" employment opportunities for persons unable to secure jobs in the competitive labour market. Funding should not be aimed at supporting non-viable business ventures, but at supporting costs associated with the special hiring practices of viable enterprises. The Provincial Department of Economic Development and Tourism and the Federal Department of Employment and Immigration and representatives from voluntary organizations (representing service providers and advocacy groups) should participate actively in designing these programs.

EMPLOYMENT TRAINING - programs designed to increase the employability of mentally retarded adults. With a focus on "job-readiness", programs should concentrate both on general work habits and marketable, career-specific skill development. Courses

developed should be of specified duration and have clear, measurable objectives. If participants do not meet "passing" criteria, they should be eligible to re-enroll. The Provincial Departments of Education and Labour and Manpower, the Federal Department of Employment and Immigration and representatives from voluntary organizations (representing service providers and advocacy groups) should participate actively in designing these programs.

PERSONAL/SOCIAL INDEPENDENCE TRAINING - programs designed to increase the competencies of mentally retarded adults in skill areas related to personal and social independence. As above, courses should be of specified duration, have measurable objectives, and be open to re-enrollment. The Provincial Department of Education and representatives from voluntary organizations (representing service providers and advocacy groups) should participate actively in designing these programs.

- 2) THAT CURRENT FUNCTIONS OFFERED THROUGH PROVINCIAL VOCATIONAL REHABILITATION SERVICES BE SHIFTED TO THE DEPARTMENTS AND/OR AGENCIES MANDATED TO PROVIDE THESE SERVICES TO THE GENERAL PUBLIC (see recommendations 3 through 9). TO FACILITATE THE RECOMMENDATIONS, THE CURRENT MINISTRIES MUST MEET WITH THEIR FEDERAL COUNTERPARTS TO WORK OUT DETAILS.
- 3) THAT THE CANADA EMPLOYMENT AND IMMIGRATION COMMISSION (C.E.I.C.) BE ASSISTED AND MANDATED TO DEVELOP AND PROVIDE VOCATIONAL EVALUATION PROGRAMS FOR MENTALLY RETARDED ADULTS.

Such programs should be utilized to assess the current skill levels of the individual and/or further training requirements.

- 4) THAT THE C.E.I.C. ASSUME RESPONSIBILITY FOR DELIVERING OR ARRANGING VOCATIONAL COUNSELLING AND REFERRAL SERVICES TO MENTALLY RETARDED MEN AND WOMEN IN MANITOBA.
- 5) THAT COMMUNITY COLLEGES AND/OR UNIVERSITIES ASSUME RESPONSIBILITY FOR CAREER-ORIENTED TRAINING PROGRAMS FOR MENTALLY RETARDED PERSONS.

Courses should range from general content (such as an orientation to the importance of work), to training in general work habits, to training for job-specific skills.

- 6) THAT THE PROVINCIAL DEPARTMENT OF LABOUR AND MANPOWER DEVELOP EMPLOYMENT PREPARATION INITIATIVES FOR MENTALLY RETARDED ADULTS (initiatives similar to the New Careers program).
- 7) THAT THE CANADA EMPLOYMENT AND IMMIGRATION COMMISSION (C.E.I.C.) ASSUME RESPONSIBILITY FOR DELIVERING OR ARRANGING EMPLOYMENT SERVICES FOR MENTALLY RETARDED PERSONS.

Where possible, existing C.E.I.C. employment services should be adapted to include mentally retarded persons. Where necessary, special employment programs may be developed. Such services should include:

- assisting persons to locate suitable jobs;
- assisting persons to secure jobs (i.e. application procedures);
- providing on-site job orientation/adjustment services;
- providing workplace adaptation supports to employees and employers;
- providing on-the-job skill training;
- providing job-stabilization supports (i.e. follow-up services).

The Provincial Employment Services and Vocational Rehabilitation Services and representatives from voluntary organizations (representing service providers and advocacy groups) should participate actively in designing these services.

- 8) THAT THE PROVINCIAL DEPARTMENT OF ECONOMIC DEVELOPMENT, DRAWING ON THE RESOURCES OF THE DEPARTMENT OF COOPERATIVE DEVELOPMENT, AND THE FEDERAL DEPARTMENTS OF C.E.I.C. AND THE RELEVANT FEDERAL DEPARTMENTS ASSUME RESPONSIBILITY FOR STIMULATING AND SUPPORTING THE DEVELOPMENT OF INTEGRATED "SHELTERED" BUSINESSES BASED ON COOPERATIVE OR AFFIRMATIVE INDUSTRY MODELS.

Such businesses are equally committed to the employment of mentally retarded persons and to managing economically viable enterprises.

- 9) THAT CONTINUING EDUCATION (ADULT EDUCATION) ASSUME RESPONSIBILITY FOR PROGRAMS OFFERING PERSONAL/SOCIAL INDEPENDENCE TRAINING FOR MENTALLY RETARDED ADULTS (including people with severe and multiple handicaps).

Such programs should focus on life enriching, competency building courses.

- 10) THAT RESIDENTIAL SERVICES CURRENTLY OPERATED BY PROVINCIAL VOCATIONAL REHABILITATION SERVICES BE TRANSFERRED TO APPROPRIATE NON-PROFIT OPERATORS OF RESIDENTIAL SERVICES.

- 11) THAT PROVINCIAL VOCATIONAL REHABILITATION SERVICES BE RECONCEPTUALIZED AND SIGNIFICANTLY RESTRUCTURED TO PERFORM THE FOLLOWING FUNCTIONS:

BEING THE FIXED POINTS OF RESPONSIBILITY FOR THE QUANTITY AND QUALITY OF VOCATIONAL SERVICES AVAILABLE TO MENTALLY RETARDED PERSONS THROUGH PRIVATE AND PUBLIC AGENCIES.

KEEPING IN TOUCH WITH THE LATEST INNOVATIONS IN SERVICE DESIGN, TEACHING TECHNOLOGIES, AND TECHNOLOGICAL AIDS AND MAKING THEM AVAILABLE TO MANITOBA'S MENTALLY RETARDED CITIZENS.

- 12) THAT THE PROVINCIAL DEPARTMENT OF LABOUR AND MANPOWER DEVELOP MECHANISMS TO MONITOR THE EMPLOYMENT SITUATIONS OF MENTALLY RETARDED PERSONS TO INSURE FAIR LABOUR PRACTICES.

Where possible, existing mechanisms should be adapted to meaningfully include mentally retarded persons. Where necessary, special mechanisms may be developed. Initially, special attention should be focused on the issues of wages, legal protection and working conditions.

For secondary implementation:

- 13) THAT THE C.E.I.C. INCLUDE MENTALLY RETARDED PERSONS AS A TARGET GROUP FOR THEIR SPECIAL EMPLOYMENT INITIATIVES.

Initially, action should be taken to ensure job opportunities for mentally retarded persons through the Winnipeg Core Area Redevelopment Program and C.C.D.P. programs.

- 14) THAT THE C.E.I.C. ALTER EXISTING PROGRAMS, AND STRUCTURE FUTURE PROGRAMS, TO MEANINGFULLY ACCOMMODATE THE NEEDS OF MENTALLY RETARDED PERSONS.

These include such programs as General Industrial Training (G.I.T.), Canada Manpower Institutional Training Program (C.M.I.T.P.), Local Employment Assistance Program (L.E.A.P.), etc.

- 15) THAT THE C.E.I.C. WORK WITH EMPLOYERS IN THE PRIVATE AND PUBLIC SECTORS TO DEVELOP GROUP WORK STATIONS FOR MENTALLY RETARDED PERSONS.
- 16) THAT THE C.E.I.C. DEVELOP AND IMPLEMENT EDUCATIONAL PROGRAMS TO PROMOTE THE EMPLOYMENT OF MENTALLY RETARDED PERSONS IN THE PRIVATE AND PUBLIC SECTORS, AND DEVELOP INCENTIVE PROGRAMS TO ENCOURAGE SUCH ACTION.
- 17) THAT AFFIRMATIVE ACTION PROGRAMS FOR MENTALLY RETARDED PERSONS BE IMPLEMENTED WITHIN BOTH FEDERAL AND PROVINCIAL SERVICES AND CROWN CORPORATIONS.

FURTHER CONSIDERATIONS

In implementing the foregoing recommendations, the following issues must be taken into consideration:

The Inclusion of Severely and Multiply Handicapped Persons. Such people have historically been neglected by service designs in this province. Even now, they are actively discriminated against in community residential and occupational programs and even in de-institutionalization efforts. Special attention must be given to ensure that they are afforded maximum participation and benefits from new service designs.

Consumer Participation. Special attention should be given to ensuring adequate and appropriate input from consumers at all levels of decision-making.

Rural/Urban Disparities. Services must be designed to accommodate to regional disparities. Factors to be considered include local economic bases, local educational resources, geographic distances from important resources, the number of persons in need of service within a particular locale, etc.

Comprehensiveness. Every effort should be made to design a range of services to meet the diversity of needs outlined in earlier portions of this text. Every program component that is missing will hinder the effectiveness of existing ones. In addition, every effort must be made to design a system which can accommodate all the persons in need of its services. Not only the needs of persons currently in community services must be considered, but also those at home, those waiting to leave the institutions and those to graduate from the school system.

Normalization/Integration. Normalization, a widely-accepted ideology which promoted the qualitative development of services and its major corollary--the principle of integration--must be understood and implemented by service designers in order to safeguard the quality and effectiveness of the resulting service.

Retraining Programs. We are on the verge of seeing industry dramatically reshaped by emerging technologies. The wide scale introduction of these technologies will render large portions of the work force obsolete. It will also, hopefully, create many new jobs. Initiatives must be taken to include mentally retarded men and women in retraining programs resulting from these developments. The CEIC, especially, must play a significant role in these retraining efforts.

SECTION 6 - RECREATION AND LEISURE SERVICES

STATEMENT OF PRINCIPLES

We affirm that all persons who are mentally retarded have the right:

- to participate in and benefit from recreation and leisure time opportunities,
- to choose their own recreation and leisure time activities,
- to be involved in the planning, implementation, and evaluation process of recreation and leisure time activities,
- to have access to all existing and potential generic recreation and leisure time opportunities, and
- to participate in recreational pursuits with the support required for meaningful involvement.

THE CURRENT SITUATION

1. Although there are several examples in Manitoba of progressive and adaptive recreation programs, there still exists a traditional attitude of offering highly specialized segregated recreation programmes in specialized settings for disabled persons. This has resulted in:
 - A. a lack of action to ensure opportunities for disabled persons to become full members of the community through participation in regular leisure services;
 - B. a lack of progressive social, psychological and physical skill development opportunities for people with disabilities which would enable their potential total involvement in community leisure services;
 - C. perpetuation of physical and psychological barriers imposed upon disabled persons by society at large.
2. Recreation personnel and paraprofessionals, in general, have not received training aimed at understanding and implementing the normalization of leisure service delivery systems which would encourage the progressive integration of the disabled into the community.
3. The low economic status of mentally retarded people has prohibited opportunities through involvement in commercial recreation services.

4. Current inefficiency of government, voluntary, professional, and community resources has made it difficult for disabled persons to become involved in more meaningful leisure experiences because of:
 - A. a lack of an overall co-ordinated effort among public voluntary and private sectors to enable regular leisure services for disabled persons;
 - B. a lack of coordination between community agencies to provide normalized public services in general, as well as development opportunities geared at potential full use of these services (transportation, education, etc.);
 - C. duplication of leisure services (example: leisure counselling is offered for seniors at the senior citizen's centre by senior leisure counsellors; leisure counselling is offered for mentally retarded people in an institution by 'specialized' persons; leisure counselling for the general public is offered by a recreation department);
 - D. continued financial support for developing more specialized services and facilities when adaptation of existing programmes and facilities would be appropriate.

RECOMMENDATIONS

1. MUNICIPAL RECREATION DEPARTMENTS SHOULD INITIATE A COORDINATED EFFORT WITHIN THEIR COMMUNITIES TO PROVIDE THE RESOURCES AND OPPORTUNITIES NECESSARY FOR DISABLED PERSONS TO BECOME INVOLVED IN REGULAR RECREATION SERVICES BY:
 - A. contacting the general public, disabled persons, advocate agencies, volunteer agencies, institutions, other city departments, politicians, social agencies, etc., in order to promote a new attitude toward providing community opportunities including recreation for disabled persons;
 - B. re-educating and upgrading the skills of recreation personnel so that they understand and are able to cope with the concepts and reality of integration and normalization;
 - C. developing an appropriate system of physical, psychological, and social skill development opportunities in order to allow disabled persons to function at their highest possible levels of desired involvement in regular leisure services;
 - D. providing resources and the opportunity within every programme and facility for integration of disabled persons.

SECTION 7 - RESIDENTIAL SERVICES

STATEMENT OF PRINCIPLES

We believe that all people, however severe their disabilities, must be permitted opportunities to live among their non-disabled peers and vice versa. We believe that people who have been classified as retarded should have available to them the patterns and conditions which characterize the mainstream of society. Indeed, we believe that support services should be available to promote the fullest possible integration of people with disabilities into communities.

The continued segregation of retarded persons into institutions and other forms of residential ghettos can only lend credence to the many fears of, and myths and prejudices against people with disabilities. And no amount of scientific language can mask the fact that segregation benefits no one. We find no reasons, either based in data or moral belief, to support the practice of isolating or segregating retarded persons from the mainstream of communities. If people need services, let them receive them in typical communities. Rational scientific inquiry and moral convictions do not support other conclusions.

The issue of institutionalization¹ strikes at the very core, the very essence of our common humanity. What is at issue here is fundamental human rights and the quality of the lives of human beings. To claim that some people cannot learn, to place those same people in isolated institutions, and then to suppose that the dignity and well being of those people can be protected, let alone enhanced, is to deny history. And to suggest that some people cannot and should not live amongst their fellow human beings is to deny our shared humanness.

¹ Definition - Institution. For the purposes of this report, the use of the word institution has the following characteristics:

- 1) congregate living in a group larger than an average family;
- 2) maintenance of most activities of life (residential, social, vocational, leisure, educational, creative) within one administrative entity; and
- 3) some degree of isolation and separation from the ebb and flow of community life.

THE CURRENT SITUATION

The Province of Manitoba has the second highest rate of institutionalization of persons with mental retardation in Canada (Quebec is first). The cost to the taxpayers of Manitoba is 33 million dollars annually. The cost in human terms to the individuals and their families is appalling.

The historical basis for the congregation of individuals in large segregated settings has been a traditional societal belief that mentally handicapped persons are a menace to themselves and others. This belief is supported in Manitoba's Mental Health Act.

In recent years, with the general development of community based services, the justification for the use of institutions has been that the needs of some handicapped persons are so complex and exotic that they can only be met by the use of large congregate care facilities.

The present residential service system provokes feelings of frustration and insecurity in consumers and service operators. The part of the system that is based on the group home model is highly dependent on the individual consumers ability to adjust to the demands of living with as few as three or as many as twenty other handicapped persons. High rates of staff turnover, due to inadequate pay and training, only compounds the sense of insecurity.

For severely and multiply handicapped individuals (numbering in the hundreds) the situation is desperate. There are only two facilities with a total of fourteen bed spaces available in the Province.

The present high priority waiting list for residential services in Winnipeg alone is reported at 130+ . The typical implementation time for groups wishing to provide new residential service is two to three years.

The high rate of demand and the slow pace of development has created a seller's market for residential services where individuals with complex physical and emotional needs are rejected in favor of persons who will make less demands on under resourced programs. This also makes individuals and their advocates reluctant to raise legitimate concerns about inappropriate or inadequate service for fear of "losing what they have".

In initiating the process of deinstitutionalization and beginning the phasing out of institutions, government will encounter conflict with powerful vested interests such as:

- a) people whose careers and power are based on the control of resources allocated to the institutional model of service delivery;

- b) people who fear loss of their jobs through reallocation of resources;
- c) towns whose economic base is reliant on the large workforce of institutions.

RECOMMENDATIONS

- 1) THAT GOVERNMENT CEASE ALL ADMISSIONS TO THE MANITOBA SCHOOL, PELICAN LAKE TRAINING CENTRE AND ST. AMANT AND CREATE AN ADEQUATE COMMUNITY RESPONSE TO THE NEEDS OF THOSE REFERRED FOR ADMISSION. TO BE ACCOMPLISHED BY APRIL 1985
- 2) THAT GOVERNMENT STOP THE TRANSFER OF CHILDREN FROM THE ST. AMANT CENTRE TO THE MANITOBA SCHOOL.
- 3) THAT THE MANITOBA SCHOOL AND PELICAN LAKE TRAINING CENTRE BE PHASED OUT BY THE YEAR 2,000.
- 4) THAT THE MINISTER OF COMMUNITY SERVICES APPOINT A FIVE PERSON COMMITTEE CONSISTING OF:

- Manitoba Government Employees Association (M.G.E.A.)
- Representative of institution staff
- Representative of the Social Policy Committee
- C.A.M.R. (Manitoba Division)
- M.L.A. without portfolio - to act as chairperson.

THE PURPOSE OF THIS COMMITTEE WOULD BE TO CREATE OPPORTUNITIES FOR ALTERNATE EMPLOYMENT FOR EACH EMPLOYEE OF THE INSTITUTIONS, INCLUDING EMPLOYMENT IN COMMUNITY PROGRAMS OR IN THE CIVIL SERVICE.

- 5) THAT THE MINISTER OF COMMUNITY SERVICES AND CORRECTIONS DISCONTINUE THE USE OF THE INDEPENDENT CONTRACTOR AGREEMENTS (CURRENT FORM OF PAYMENT TO SPONSORS) IN GROUP HOMES.
- 6) THAT PRESENT FUNDING FORMULAS FOR GROUP RESIDENCES BE REVIEWED TO ENSURE PERSONS PROVIDING RESIDENTIAL SERVICES ARE PAID AT LEAST MINIMUM WAGE.
- 7) THAT EXISTING GROUP HOME OPERATIONS BE REVIEWED AND STABILIZED.
- 8) THAT THE MINISTER OF COMMUNITY SERVICES AND CORRECTIONS ESTABLISH THE FOLLOWING PRIORITIES FOR SERVICE DEVELOPMENT:
 - severely/multiply handicapped persons
 - children turning 18 and leaving the child welfare system

- persons at risk of institutional placement due to lack of community resources
- 9) THAT THE MINISTER OF COMMUNITY SERVICES AND CORRECTIONS ACCELERATE THE USE OF SUPPORTED PERSONALIZED LIVING ARRANGEMENTS TO ALLEVIATE THE LACK OF COMMUNITY RESIDENTIAL OPTIONS.
- 10) THAT THE REGIONAL BOARDS ESTABLISH A FLEXIBLE COMMUNITY BASED EMERGENCY SHELTER AND SUPPORT CAPACITY FOR INDIVIDUALS AT RISK OF INSTITUTIONAL PLACEMENT

NOTE: See RECOMMENDATIONS of SECTION 1 - PLANNING AND ORGANIZATION regarding the role of citizen, community-based boards in enabling implementation of all of these recommendations.

APPENDIX I

ILLUSTRATIONS OF COMMUNITY LIVING THE BEST IN NORTH AMERICA

INTRODUCTION

The last two decades have witnessed a dramatic change in the way we think and act towards individuals who are labelled mentally retarded. In communities across Canada, this change is expressed in the emergence of a range of community living options, a range of supports for employment and job trainings, and the increasing integration of handicapped children into the regular school system.

Evidence of these changes at the policy level is widespread. Perhaps the best known examples are the UN Declaration on the Rights of Mentally Retarded Persons; the United States President's Committee on Mental Retardation; and the Canadian Special Committee on the Disabled and the Handicapped. All three point to the fundamental need for societies and communities to develop supports for handicapped people and their families that can ensure what is a right is also a reality.

More recently, there is a growing awareness of and commitment to the fact that people who live with severe, profound and multiple handicaps not only should enjoy the same rights, but can be supported to live in the community. The purpose of this paper is to present a number of existing examples of ways in which individuals who live with severe, profound and multiple handicaps are being supported successfully in the community, plus examples from the literature documenting the effects of community living on the growth and development of these individuals.

I. Places to Live

A. For Children

The best place for a child to live, in most cases, is in his or her own home with the natural family. Some children can be very demanding and exhaust the patience and energies of their families if the parents are not well supported. There are examples in almost every community in North America of programs that provide direct support to families so that they can support the growth and development of their children in their own homes. Examples include Parent-to-Parent programs, Pilot Parents, Extend-a-Family, infant stimulation programs, and such programs as the Direct Home Services program in Newfoundland and Labrador. In each case, support is being successfully provided to families whose children live with the broadest range of handicaps.

In-home support on a much more consistent and universal basis than is currently the case is the preferred approach. Alternative accommodation should only serve as back-up to approaches aimed at keeping the natural family together.

with at most one or two other handicapped people with a wide range of amounts and types of staff support.

Medical and other supports are purchased from community professionals or from core teams of professionals who serve the county on an itinerant basis. Staffing patterns for individuals are routinely changed to reflect the growing independence, growth and development of the individual. Individuals with severe behaviour problems, for instance, begin by living in a house with very intensive staff support which is gradually lessened as problems decrease and competency increased. As indicated, one or two other mutually compatible adults who live with a mental handicap can move into the house.

Both the CLB and Pennsylvania approaches are based on the development of places for individuals to live in response to the strengths and needs of the individuals for whom support is provided. In other words, places to live and accompanying supports are developed for individuals and are changed to meet the changing strengths and needs of the individual. This stands in marked contrast to the development of a group home into which an individual must fit and requires him to move if his needs change.

Program: Services for Community Living, Holyoke, Mass.

The families of four women were instrumental in developing a residential program to respond to their daughters' needs. The women were described as severely handicapped, non-ambulatory, non-verbal, and completely dependent when the program began. They now live in a wheelchair-accessible apartment, attend vocational programs, have learned to communicate (non-verbally); and are making plans to live in more independent settings with fewer people.

II. Places to learn and Work

A. Children's Developmental and Educational Services

In any community the primary resource for child development is the public school system. An increasing number of school systems are developing the capability to respond to the educational needs of children who have special needs in non-segregated environments. Ten such school districts have been identified in the United States as having very promising features (Bangor, Maine; Birmingham, Alabama; DeKalb, Illinois; Honolulu, Hawaii; Madison, Wisconsin; Mt. Shasta, California; Portland, Maine; Tacoma, Washington; Urbana, Illinois). Movement toward school integration is evident across the United States as a strong trend and is mandated in many jurisdictions.

The trend toward school integration is steadily growing in Canada as various provinces are changing or examining existing legislation.

Program: Market Lane Public School (Toronto, Ontario)

Individuals are being successfully integrated with supports into regular classes at this school. The program involves children who live in the apartments sponsored by Ceci's Homes for Children and who are considered to be severely, profoundly and multiply handicapped.

Program: PEOPEL (Port Colbourne, Ontario)

"PEOPEL" stands for Physical Education Opportunity Program for Exceptional Learners. It involves the pairing of handicapped children with non-handicapped peers in a variety of educational program areas. The program was developed in the United States and was initially implemented in Ontario at a high school in Port Colbourne.

Community: Labrador City, Newfoundland and Labrador

School integration in Labrador City has been greatly facilitated by the extensive use of trained volunteer aides in the classroom. A volunteer teacher aide training program was developed by the Local Association. Home-based teachers and the corps of volunteers assist handicapped children in normal classrooms.

The successful experience of the program with children who are considered multiply handicapped, some with very limited physical capabilities, has helped spark community-wide efforts to ensure that children who are severely, profoundly and multiply handicapped can be continually supported in the community throughout their lives.

The wide range of creative approaches to school integration developing across Canada was preceded in many communities by the integration of pre-school and early intervention programs. Parent satisfaction with integrated programs for young children has resulted in increasing pressure from parents for integration of entire school systems. This trend is continuing to gain momentum as parents and professionals see the difference in children's learning that occurs where the children have access to non-handicapped peer models. The non-handicapped children are also beginning to interact with their handicapped classmates as fellow students rather than groups of children isolated in segregated settings.

B. Employment and Job Training Programs

To date, vocational programs in Canada that involve adults labelled severely, profoundly and multiply handicapped are primarily of an "activity/developmental centre" nature. The focus is on developmental or recreational activities that are directed at keeping adults occupied or assisting their growth and development in self-help skill areas.

There are, however, programs that have developed in the last decade that demonstrate two key facts:

1. adults who are labelled severely, profoundly and multiply handicapped can both learn and perform work that is income producing and complex in nature.
2. jobs can be found for adults who live with a mental handicap that respond both to their individual strengths and needs and to the economy of their communities.

Program: Specialized Training Program (Eugene, Oregon)

The S.T.P. approach is now being applied in nine businesses in the Northwest United States. A total of 163 workers are involved, all of whom are labelled "severely or profoundly retarded", many of whom live with additional physical and mental handicaps.

The longest running program, located in Eugene, has a total commercial revenue of \$50,000 and the workers earn an average monthly wage of \$109. The program involves intensive, hands-on training and follow-up. Contracts are primarily in the electronics and machine assembly areas.

According to the Washington State Department of Social and Health Services newsletter, with reference to the S.T.P. business in Seattle,

The program was started five years ago in the belief that extremely mentally handicapped people can be trained to perform highly skilled work on products useful to industry. The results have thoroughly verified this assumption. Olympus presently employs 18 adults in the below 40 I.Q. range. Many are able to earn enough to contribute substantially to their own living expenses. All are able to live with some degree of independence, thanks to their job training ...

Community: Madison, Wisconsin

Two programs in Madison compliment one another and demonstrate the dramatic impact that can result when the school system is involved in employment training. The Madison School System has a zero-exclusion policy that has resulted in a broad range of programs and supports for children who live with a wide range of handicaps. An integral part of the school curriculum is the involvement of handicapped students in community and work settings. By using aides, volunteers and fellow students, handicapped students are supported to learn community living and working skills. For example, three individuals who are deaf, blind, labelled "profoundly retarded" and engage in self-stimulating behaviours spend part of their day at a work placement in a hospital

unpacking I.V. bags. Graduates of the program now work in commercial and industrial settings throughout the community.

Also in Madison, Wisconsin, Vocational Education Alternatives focusses on two aspects of supports to adults: assisting them to gain access to generic job-skill development services, and, to choose, obtain and retain competitive jobs of their choice. V.E.A. provides supports to individuals who live with a range of diagnostic labels (cerebral palsy, epilepsy, mental retardation, learning disabled, mental illness, and behaviour problems). Many individuals have two or more handicaps. Many were considered to be unemployable by other vocational service providers, but have been successful in finding and holding competitive jobs.

V.E.A. employs a number of strategies to support adults in gaining access to services and getting jobs, including career awareness and exploration classes; teaching self-advocacy; working with an individual to gain access to existing services; providing transportation assistance; in-service training for professionals; outreach to employers; job development and job placement programs; job coach support; and intensive one-on-one job skill training in the work place.

During the first eight months of 1981, V.E.A. assisted 61 individuals to find competitive jobs with an 88% retention rate; 51 individuals to enroll in the area's technical college; 2 individuals to enroll in university; 37 individuals to enroll in a job skill training program; and 40 individuals to gain experience through volunteer positions.

Given the head start provided in job experience through the school system, adults who are often considered unemployable are being much more successful in becoming workers rather than trainees forever.

Conclusion

The examples mentioned above are not unique nor are they the result of extraordinary measures. They have resulted from the efforts of individuals and groups who were convinced that people who live with severe and multiple handicaps not only should but can be supported to live in the community with dignity. Taken together they point to the fact that a full range of options is possible without congregating individuals in numbers larger than ordinary families.

The references listed below are examples of the research experience that has been gained over the years. The references dealing with the benefits of community living, by and large, deal with individuals who have been labelled severely, profoundly, and multiply handicapped. They consistently point to the benefits that accrue from individuals being supported in small community homes with full involvement in community life. The cost benefit literature is less decisive. The references listed give an indication of the positive

trends that have been documented, but definitive studies linking growth and development in community arrangements with lower costs over the lifetime of individuals have yet to be done.

The indication to date, however, is that individuals who live with severe and multiple handicaps can be supported to live in the community with dignity, not merely at custodial care levels. Such individuals can be seen across North America working for competitive wages, going to school in normal settings, living at home or in family-like settings, and taking advantage of community resources that support their medical, behavioural, recreational and social needs.

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APPENDIX II

THE ADVOCACY ROLE

Experience in other settings strongly indicates that for the child's needs to be met, the family needs to feel highly confident about the responsiveness of the service system to meet its need for assistance. It is important for the family to experience continuity of support and intent, and important for them to have a "sounding board" who is knowledgeable, sympathetic, and who can help them interpret the input of diverse service providers. The needs of the child and family will not always be congruent with the needs of the service system or of any specific agency. There are occasions when the agency's interest (and thereby that of the case manager) lies in controlling or limiting the provision of service; a third party can help to insure that "system" needs do not override the needs of the child and family. The child's needs (which include meeting the needs of his family of origin and/or his foster family) are best safeguarded when an advocate -- a person who is ultimately in alliance with the child and not with the system -- is intimately involved and speaks with and for the interests of the child.

The advocacy role is difficult for some to understand or to accept. Perhaps the best analogy is in the legal system, in which a legal solicitor is commissioned by or appointed for a person to represent his interests, to be a spokesman for those interests, and to offer advice and assistance to his client in order to make sense of a complex and often mystifying system. This requires knowledge and experience about the system, and freedom from conflict of interest. In the legal arena, this role is officially sanctioned and safeguarded. We believe this role to be no less necessary for persons dependent on a complex human service system for the quality of their lives.

The advocacy role is most effective when it occurs at the invitation and sanction of the child's family of origin or legal guardian. The role is safeguarded when recognized formally by service providers.

The advocacy role involves:

- a. Identifying, in conjunction with the child and family of origin or legal guardian, the specific needs of the child and family, and acting in the role of spokesman to assist the child, his family of origin and his foster family in meeting those needs.
- b. Providing the child and family with a subjective experience of continuity and confidence that the family will be assisted to meet the needs of the child;
- c. Providing moral support and a point of reference that is free from the constraints of program management;

- d. Assisting service providers to arrange, obtain or develop services to meet the child's needs;
- e. Working with the child, the family and service providers to create a means of meeting needs which are not met (or not met appropriately) by currently available services;
- f. Providing information and advice to the family and to service providers on the child's behalf;
- g. Providing technical support and advice as required.

